Articles

Does Fear of Immigration Authorities Deter Tuberculosis Patients From Seeking Care?

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Physician groups are concerned that legislation requiring physicians to report illegal immigrants to immigration authorities will delay curative care. In particular, patients with tuberculosis may delay seeking care for infectious symptoms and spread the disease. We surveyed 313 consecutive patients with active tuberculosis from 95 different facilities to examine the relationship of immigration-related variables, symptoms, and delay in seeking care. Most patients (71%) sought care for symptoms rather than as a result of the efforts of public health personnel to screen high-risk groups or to trace contacts of infectious persons. At least 20% of respondents lacked legal documents allowing them to reside in the United States. Few (6%) feared that going to a physician might lead to trouble with immigration authorities. Those who did were almost 4 times as likely to delay seeking care for more than 2 months, a period of time likely to result in disease transmission. Patients potentially exposed an average of 10 domestic and workplace contacts during the course of the delay. Any legislation that increases undocumented immigrants' fear that health care professionals will report them to immigration authorities may exacerbate the current tuberculosis epidemic.

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Although the incidence of tuberculosis has declined in the United States throughout this century, the disease remains prevalent in much of the developing world. Its recent resurgence has coincided with rising immigration rates from these areas of high prevalence.[1] High rates of immigration have historically engendered attempts to limit immigrants' access to social services, and several states are currently considering legislation denying publicly funded health care to undocumented immigrants. Public health authorities and physician groups have expressed concern that legislation requiring providers of publicly funded services to report illegal immigrants to immigration authorities will delay curative care for infectious diseases and exacerbate the tuberculosis epidemic (B. Hayward, "Coalition Vows to Fight Immigration Initiative," *The Sacramento Bee*, June 23, 1994, p A3). Even though some policies may exclude public health functions like tuberculosis-case tracking from the list of services requiring immigration papers, these patients may not recognize their symptoms as indicative of tuberculosis. They might then delay seeking care, thus allowing the disease to spread.

Few data exist regarding the proportion of tuberculosis patients who will be affected by immigration legislation. In the United States, 22% of patients with tuberculosis were born in other countries.[2] Few studies have examined what proportion lack legal immigration papers. Similarly, basic measures of acculturation such as linguistic proficiency or length of time in the United States are lacking for patients with tuberculosis. Nor has any study directly examined the prevalence of fear of immigration authorities in these patients. Even if few patients have such fear under the current law, how long they delay seeking care will shed light on the extent to which policies that increase fear will increase delay. Yet no studies of patients with tuberculosis have examined the effect of immigration and cultural variables on delay.

If the public health system diagnoses most cases of tuberculosis as a result of contact tracing or screening high-risk groups, the effect of immigration on the delay in seeking care becomes less crucial to ascertain. Recent studies have cast doubt on the efficacy of traditional case-tracking methods.[3] Yet little is known about whether patients with tuberculosis come to attention because they seek care for symptoms or because public health personnel identify them.

Los Angeles, California, lies at one of the epicenters of the tuberculosis epidemic—second only to New York City. Unlike the nation as a whole, immigrants make up most of the active tuberculosis cases in Los Angeles,

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making it an ideal site from which to generalize to other areas considering limiting undocumented immigrants' access to health services.[4] We report the results of a Los Angeles County registry-based survey examining the relationship of symptoms, immigration-related variables, and tuberculosis patients' delay in seeking medical care.

Methods

Study Population

The law requires health care professionals, laboratories, and governmental agencies to report all suspected and confirmed cases of tuberculosis in Los Angeles County (excluding the municipalities of Pasadena and Long Beach) to the Los Angeles County Tuberculosis Control Registry. We prospectively identified 526 consecutive, confirmed cases of active tuberculosis reported between April and September 1993, excluding children, prisoners, and persons who had died. Also excluded were persons who could not speak one of five common languages in our study population: English, Spanish, Mandarin, Tagalog, or Vietnamese.

Data Collection

We sent potential respondents a letter describing our study and providing them with a phone number to call if they did not wish to participate. Trained bilingual interviewers called all eligible patients using the phone numbers provided by the registry, clinics, directory assistance, or friends or relatives listed in medical records. Because telephone surveys miss homeless persons, interviews were conducted in person at soup kitchens, shelters, and a specialized county clinic for the homeless. Interviewers made an average of 16 attempts to contact respondents. We abstracted demographic and clinical information—radiographic and microbiologic results—from the registry.

After giving informed consent, subjects responded in their preferred language. Interviewers used a structured, symptom-based form to elicit ethnicity, country of birth, length of time in the United States, reason for seeking care, legal status, English proficiency, the language spoken by their health care professional, number of possibly exposed contacts, symptoms, and delay in seeking care. Items were derived from previously validated instruments.[5-8] Researchers then conducted a series of focus groups of tuberculosis patients, evaluating and modifying each item for face and content validity. The translated form for each study language was developed from the English original using back-translation techniques.

The survey instrument defined tuberculosis symptoms as one or more of the following occurring in the previous two years and lasting two weeks or more: cough, hemoptysis, fatigue, fever, weight loss, swollen glands, diarrhea, anorexia, night sweats, pleuritic pain, or lymphadenopathy. Contacts with possible exposure to tuberculosis were persons living in the respondent's household or working in the same room for more than an hour each day.

Fear of immigration authorities was assessed by asking, "Were you afraid going to the doctor might cause trouble with the immigration authorities?" We chose to word the question this way because focus group and pilot data indicated that although subjects understood this to mean possible deportation, specifically mentioning deportation resulted in high rates of missing data.

Data Analysis

Previous research has shown that domestic contacts with exposure to active cases for more than 60 days often show signs of infection.[9] We classified each symptomatic respondent into two groups: those who delayed more than 60 days from the onset of symptoms to first contact with the medical care system, and those who delayed 60 days or less. For the analysis of delay, serious symptoms were defined as cough, hemoptysis, fever, or night sweats. χ^2 Tests and logistic regression techniques from the SAS statistical package were used to examine the associations between characteristics and a delay of more than 60 days in seeking care.[10] Analyzing delay using a continuous outcome measure and nonparametric comparisons did not change the direction or statistical significance of the bivariate results.

To check the reliability of the interview data and to ensure quality control, the principal investigator (S.A.) or project managers (Lorraine Chun, MPH, or Mike

TABLE 1.—*Demographic, Clinical, and Immigration-Related Characteristics of the Study Population*

Variable	Respondents, No.	(%)
Demographic		
Male	195	(62)
Median age, yr	41	
Ethnicity		
Latino	152	(48)
Asian	72	(26)
African American	38	(12)
White	32	(11)
Other	7	(2)
Clinical		
Abnormal radiograph	271	(88)
Abnormal x-ray film and/or positive TB culture	305	(97)
Cavitary lesion	62	(21)
Positive AFB smear	164	(55)
Any TB symptom lasting 2 weeks or more	248	(79)
Mean no. of exposed contacts	10	
Immigration		
Foreign born	215	(69)
Arrived in US as an adult	182	(60)
Not native English speaker	193	(75)
Poor English ability by self-report	78	(25)
Provider did not speak subject's language*	79	(32)
Language problem in seeking care*	29	(13)
No documents	48	(20)
Feared immigration authorities*	15	(6)

AFB = acid-fast bacilli, TB = tuberculosis

* Only asked of 248 symptomatic patients.

TABLE 2.—*Reasons Patients With Tuberculosis (TB) Sought Care**

Reason	Respondents, No.	(%)
TB symptom	161	(53)
Other symptom	55	(18)
Non-TB medical condition	47	(15)
Screening high-risk groups	31	(10)
Contact training	4	(1)
Other reasons	10	(4)

* Percentages do not add up to 100% due to rounding.

Wada, MD) readministered the instrument to 23 subjects during the data collection process and found only rare inconsistencies. We also compared registry and interview values for variables that could be derived from both sources—age, sex, ethnicity, length of time in the United States, and country of birth—and found good agreement.

Results

Of the 526 identified cases, we were able to contact 365. A total of 313 completed the interview for an overall response rate of 60%. Registry information showed no significant differences between respondents and nonrespondents by age, ethnicity, sex, the proportion born abroad, or radiographic or microbiologic results. A total of 95 different offices, laboratories, agencies, and hospitals reported active cases during the study time period.

Table 1 summarizes the composition of the study group. Subjects were predominantly men. Latino and Asian were the largest ethnic groups. Virtually all subjects had abnormal radiographs or cultures indicating infectiousness. Many had abnormalities indicative of even greater infectiousness: cavitary lesions (21%) or acid-fast bacilli on sputum smear (55%). Subjects possibly exposed an average of ten domestic or workplace contacts.

Immigrants made up more than two thirds of the subjects. Of the immigrants, 85% (60% of total population) arrived in the United States as adults and thus were probably less well acculturated than immigrants who arrived as children. Many patients reported language difficulties: three fourths said they preferred a language other than English, a fourth rated their English ability as poor, a third did not speak the same language as their physician, and one in ten symptomatic patients said that language problems deterred them from seeking care. Of the 255 (71%) patients who responded to the question ascertaining legal status, more than a fifth said they had no immigration documents allowing them to reside in the United States. Only 6% of symptomatic patients felt that fear of immigration authorities had delayed their care.

The preponderance of patients (71%) reported that physicians discovered their tuberculosis when they sought care for a symptom (Table 2). Another 15% were diagnosed in the course of seeking care for another medical condition. Only one in ten said they had participated in screening programs, and only four patients (1%) reported that public health authorities had identified them as contacts of infected patients.

A total of 248 patients had tuberculosis symptoms and are included in the analysis of delay. Only 20% of the study group of patients with active tuberculosis delayed more than 60 days, a period of time that has been shown to result in signs of infection in exposed contacts. Table 3 shows the proportion of patients who delayed more than 60 days by demographic, clinical, and immigration variables. Asians tended to delay longer, as did those who cited language problems, although these trends were not statistically significant. More than 47% of those who cited fear of immigration authorities delayed more than 60 days, as compared with 18% of those who did not cite fear (P = .007). Respondents who feared immigration authorities were almost four times as likely (odds ratio 3.89; 95% confidence interval 1.34 to 11.36) to delay seeking care. This association persisted after adjusting for age, the presence of a serious symptom, cavitary lesion, and positive smear.

Discussion

Many variables associated with recent immigration are common in patients with tuberculosis, although in Los Angeles County in 1993, few patients feared that seeking care would result in difficulties with immigration authorities. Many undocumented patients may be aware that most health care professionals do not report information on legal status to the Immigration and Naturalization Service. Indeed, since the late 1980s,

TABLE 3.—*Associations With Delay in Seeking Care for Tuberculosis-Related Symptoms*

Variable	Delayed >60 Days, No.	(%)	Delayed ≤60 Days No.	(%)
Overall	49	(20)	199	(80)
Demographic				
Age <65 yr	43	(21)	161	(79)
Male	26	(17)	176	(83)
Ethnicity				
Latino	22	(17)	106	(83)
Asian	13	(29)	32	(76)
White	3	(13)	21	(87)
African American	5	(17)	24	(83)
Clinical				
Serious symptoms	12	(14)	71	(86)
Cavitary lesion on radiograph	13	(27)	35	(73)
Positive AFB smear	24	(22)	85	(78)
Immigration				
Foreign born	34	(20)	135	(80)
Arrived in US as an adult	29	(23)	99	(77)
Poor English ability	12	(20)	50	(80)
Language problem in seeking care	7	(25)	20	(75)
No documents	8	(19)	34	(81)
Feared immigration authorities	7	(47)	8	(53)
Did not fear immigration authorities	40	(17)	178	(83)

AFB = acid-fast bacilli, TB = tuberculosis

* Only asked of 248 symptomatic patients

many states have enacted regulations that prohibit sharing information on the legal status of state-funded patients for the purposes of deportation.[11-13]

Our data also indicate that most patients with tuberculosis come to attention because they seek care for symptoms or another nontuberculous medical condition. Most of the symptoms such as cough, fatigue, and weight loss would not require emergent treatment. Comparatively few patients with active disease were found through screening programs or contact tracing. Even if legislation restricting access of undocumented immigrants to health services allowed for emergent treatment and population-based preventive services, the diagnosis and treatment of many patients with active tuberculosis would nonetheless be affected.

Although it was uncommon, fear of immigration authorities was the cultural variable most closely associated with symptomatic patients delaying care. This association was independent of previously shown adjustors for infectiousness and severity: age, symptoms, and radiographic and microbiologic results.[14] Any increase in the fear of immigration authorities that patients experience when seeking medical care is likely to increase the delay between onset of symptoms and first contact with the medical care system. Because each patient possibly exposes an average of ten contacts to the disease during the course of delaying care, such an increase would spread tuberculosis beyond those who delay.

Our study suffers from several limitations. Like all studies of delay in seeking care,[15,16] our survey cannot evaluate the barriers to access faced by patients who never saw a physician. The chronic, symptomatic, progressive nature of the disease should eventually result in physician contact and minimize this bias, however. Moreover, concerns about the proposed legislation would persist because any residual bias would underestimate the prevalence of the fear of immigration authorities and its effect on delay in seeking care. Our study may also suffer from the limitations of the accuracy of self-reported data. The overall response rate was 60%, which may lead to a response bias. Respondents and nonrespondents did not differ on clinical or demographic variables available from the tuberculosis registry, however, and this level of response is common in studies of indigent populations.[17] About 30% of respondents declined to give their legal status. Because those who refused were presumably more likely to lack legal papers, the data provide a minimum estimate of the proportion of undocumented immigrants with active tuberculosis susceptible to a fear of immigration authorities.

To our knowledge, this is the first survey of patients with tuberculosis that examines the relationship of immigration and delay in seeking care. The broad registry-based sampling technique should ensure a study group that can be generalized to other areas with a large proportion of cases of tuberculosis in immigrants. If future research confirms our findings, any policies that increase undocumented immigrants' fear that health care professionals will report them to immigration authorities may exacerbate the current tuberculosis epidemic.

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